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**Changes in Families' Caregiving Experiences through Involvement as Participants then
Facilitators in a Family Peer-Education Program for Mental Disorders in Japan**

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MASAKO KAGEYAMA*
KEIKO YOKOYAMA†
YUKAKO NAKAMURA‡
SAYAKA KOBAYASHI

*Department of Community Health Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan.

†Department of Nursing, Faculty of Health Sciences, Saitama Prefectural University, Saitama, Japan.

‡Department of Psychiatry, Nagoya University Graduate School of Medicine, Aichi, Japan.

§National Center of Neurology and Psychiatry, National Institute of Mental Health, Tokyo, Japan.

Correspondence concerning this article should be addressed to Masako Kageyama, Department of Community Health Nursing, Graduate School of Medicine, the University of Tokyo, 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-0033 Japan. E-mail: kageyama-ky@umin.ac.jp.

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Abstract

A family peer-education program for mental disorders was developed in Japan, similar to existing programs in the U.S. and Hong Kong. Families that serve as facilitators in such programs may enhance their caregiving processes and thereby, their well-being. The current study's aim was to describe how families' caregiving experiences change, beginning with the onset of a family member's mental illness, through their involvement in a family group or peer-education program as participants then facilitators. Thus, this study was conducted in a family peer-education program for mental disorders in Japan. Group interviews were conducted with 27 facilitators from 7 program sites about their experiences before, during, and after becoming facilitators. Interview data were coded and categorized into five stages of caregiving processes: (1) withdrawing and suppressing negative experiences with difficulty and regret; (2) finding comfort through being listened to about negative experiences; (3) supporting participants' sharing as facilitators; (4) understanding and affirming oneself through repeated sharing of experiences; and (5) finding value and social roles in one's experiences. The third, fourth, and fifth stages were experienced by the facilitators. The value that the facilitators placed on their caregiving experiences changed from negative to positive, which participants regarded as helpful and supportive. We conclude that serving as facilitators may improve families' caregiving processes.

Keywords: Family Education Program; Caregivers; Mental Disorders; Program Evaluation; Qualitative Research; Self-help Groups

Changes in Families' Caregiving Experiences through Involvement as Participants then Facilitators in a Family Peer-Education Program for Mental Disorders in Japan

Among developed countries, Japan has the highest psychiatric bed ratio (OECD, 2013); however, the government has shifted its mental health policy from hospitalization to community living. More than 95% of inpatients have been discharged to their homes (Ministry of Health, Labour and Welfare, 2012). Approximately 85% of people with serious mental illness (SMI) live with their families (Chiba Prefecture Family Association of Persons with Mental Disorders, 2009), who provide daily care and medication monitoring (National Association of Family Groups on Mental Disorders, 2006). These families, having such a burden, require support to care for their ill family members with a hopeful attitude (Hernandez, Barrio, & Yamada, 2013), especially educational support in the early phases of their family member's mental illness (Reay-Young, 2001). However, only 20% of families report having access to adequate information about mental illness within three months of its onset (Minna Net, 2010). Thus, families often have limited educational resources available to them.

To provide educational opportunities for families, a family peer-education program—the “Omotenashi-Family Experiences Learning Program” (Omotenashi-FELP)—was established in 2007 in Japan, after the start of the “Family-to-Family Education Program” (FFEP) in the US and the “Family Link Education Program” (FLEP) in Hong Kong. More than 1,500 families had attended the Omotenashi-FELP as participants, and over 900 program facilitators (former participants), who were family members trained to lead the groups (facilitator), had led them by the end of March 2015. This study focuses on the Omotenashi-FELP.

Japanese Families' Attitudes about Mental Illness

Approximately 70% of primary caregivers for persons with SMI in Japan are mothers (Chiba Prefecture Family Association of Persons with Mental Disorders, 2009) who report that a sense of responsibility and guilt is their main reason for serving as the primary caregiver (Kawazoe, 2007; Mizuno & Iwasaki, 2010). Mothers often feel guilt because they gave birth to the person with SMI (Yoshii, Mitsunaga, & Saito, 2013). There is no consensus on whether ethnicity influences caregivers' burden (Suro & Weisman de Mamami, 2013). However, in the past, Japanese families have had a legal responsibility to provide care. Until 2014, Japanese law mandated for over a century that a person with a mental illness have a family guardian responsible for their treatment, which undoubtedly affected these families' sense of responsibility (Yoshida, 2011). Japanese families often describe caring for their mentally ill family member as a "lonely battle." Their isolation outside the home might be due to Japan's strong stigma against mental illness that is also found in China and Korea (Ando, Yamaguchi, Aoki, & Thornicroft, 2013; Hanzawa et al., 2009) and the lack of services for families (Minna Net, 2010). Parents' isolation inside the home may be related to accusations by their adult children with SMI of ruining their future (Matsuyama, Morita, & Ogai, 2013). Mothers of persons with SMI often lack support from their children's fathers, and therefore, tend to be isolated even among their own family members (Sato, 2006).

Descriptions of the Family Groups

This study examined self-help groups for families. Self-help groups are voluntary, small groups that provide mutual aid and support the accomplishment of a specific goal (Katz & Bender, 1976). Family groups are a valuable, albeit limited, social resource for families of persons with SMI. They address members' need for knowledge about mental illness (Norton, Wandersman, & Goldman, 1993), reduce their feelings of guilt and self-blame (Kurtz, 1997), decrease caregivers' burdens (Cook, Heller, & Pickett-Schenk, 1999), help families cope (Gidron, Guterman, & Hartmen, 1990; Norton et al, 1993), and improve parent-child

relationships (Medvene, 1989). Japan has a long history of family groups, with the establishment of a nationwide association in 1965, prior to the associations established in the UK in 1972 and the US in 1979. Minna Net, a nationwide association, has 1,200 local family groups throughout Japan's 47 prefectures. Its three main activities are mutual help, learning, and advocacy. More than 80% of the families in the family groups care for persons with schizophrenia, and more than half of the members are mothers. Approximately 20% are fathers, most of whom became members after retirement. In typical meetings, 5–20 members share updated information about each other's lives with no structured format (Minna Net, 2013). The family support groups of the National Alliance for Mental Illness (NAMI) require training to become qualified facilitators, but Minna Net has no qualifications or training. Each family group provides certain activities, such as the Omotenashi-FELP, professional lectures, and short trips, in addition to the regular meetings.

In the past, many local family groups in Japan built and managed small rehabilitation facilities voluntarily because of insufficient community services (Ikesue, 2002). Non-profit agencies began operating the rehabilitation facilities under a 2006 law, so families no longer needed to operate the facilities. It was a long-time dream for families, but the family groups lost their motivation to act (Kageyama, 2013). Thus, the main goal of family groups has shifted from advocacy for persons with SMI to the empowerment of families. The number of family groups decreased from 1,700 in 2004 to 1,200 in 2013.

Program Description

The Omotenashi-FELP is widespread in Japan and addresses the goal of transition in the context of the family group. The family groups that previously sought to accomplish new goals initiated and continued the Omotenashi-FELP (Kageyama, Yokoyama, Nakamura, & Kobayashi, 2014). The Omotenashi-FELP is a small-sized structured family peer-educational program, implemented and coordinated by a team of facilitators. Its goal is to promote the

participants' and the facilitators' empowerment. Unlike family psychoeducational programs that are a component of treatment, family peer-education programs operate independently of other treatment modalities. They are designed for families of persons with a mental illness. Although there are no criteria for inclusion in the program, over 80% of families care for persons in treatment for schizophrenia. The percentage of family members with SMI who stay at home and do not use rehabilitation services is more than half of the program's participants and a third of its facilitators. Over 90% of the participants and facilitators are parents; over 70% are females, and their average age is 65 years. The participants have less education than the facilitators and care for persons with a shorter history of SMI. The program is three hours per session, with five sessions per course. Three to six facilitators, belonging to a family group, facilitate the program as a team. In 2013, an average of 4.6 facilitators ran the program with an average of 7.9 participants at each program site. Each family group usually implements one course per year. The program was developed in the context of Japanese caregiving. It is not easy for participants and facilitators to attend twelve meetings as required by FFEP of NAMI because of their responsibilities to care for the patient at home. Since the facilitators are also caregivers, they cannot attend the program if the patient's condition worsens. Therefore, three to six facilitators may complement one another's roles (Okada, 2013), although the FFEP has two facilitators assigned to each site.

Anyone who participates in one Omotenashi-FELP course with or without membership in a family group can become a facilitator after training. There are no other criteria for becoming a facilitator. At program sites where the course is conducted for the first time, family members may become facilitators without prior experience as a participant. Recruitment of facilitators depends on each family group. Most candidates are involved regularly with the family groups and are able to go out for five to six hours to attend the program; this means that the patients' condition is sufficiently stable to be at home

unsupervised during that period of time. All facilitator candidates must attend a one-day session that includes program information, facilitator training, and practice of facilitation skills. By the time the participants become facilitators, they have met more than twice and are prepared to assume the facilitator role, share their experiences, and promote teamwork.

Program advisers with facilitator experience and additional training teach facilitator candidates, visit program sites, and support facilitators, in accordance with the program's manual. All program advisers are family members and not professionals.

The core components of the program use teaching strategies that combine sharing of experiences with the use of a textbook, peer-group facilitation, and group work-skills with positive feedback and the spirit of *Omotenashi*. These components are different from those of family psychoeducation programs, such as therapeutic relationships, education, and coping skills training (Gracio, Goncalves-Pereira & Leff, 2015). In the program, "*Omotenashi*" means "thoughtfulness towards participants; offering a courteous welcome to participants who are experiencing emotional pain, and appreciating their painful experiences," to promote their satisfaction with the program. In Japanese culture, *Omotenashi* is a necessary skill for successful facilitation. Participants and facilitators sit around a table and take turns reading two or three pages aloud from the textbook before sharing experiences related to the reading; then they provide positive feedback to one another. The program is not managed by Minna Net, but by a project team from a non-profit organization funded by a grant. The project's team of professionals and families have developed the program and its manual. Family members of the team have disseminated the program nationwide as facilitators and advisors. Members of the team were volunteers who had no conflicts of interest with the organization.

Current Research on Family Educational Programs

Quantitative evaluations of family peer-educational programs (i.e., FFEP in the US and FLEP in Hong Kong) have found that they empower participants (Chiu, Wei, Lee,

Choovanichvong, & Wong, 2013; Dixon et al., 2011). The effectiveness of the Omotenashi-FELP was evidenced by participants' and facilitators' decreased anxiety and increased empowerment (Ninomiya, 2012). Only one qualitative study has investigated FFEP participants (i.e., Lucksted, Stewart, & Forbes, 2008). Moreover, ongoing experiences of the facilitators of these programs have never been examined, although a few qualitative studies have reported that the family groups influenced families' caregiving processes (Howard, 1994; Karp & Tanarugsachock, 2000; Kawazoe, 2007). Thus, acting as facilitators of an educational program conducted in family groups may influence their caregiving experiences and the well-being of their families.

The current study's aim was to describe how families' caregiving experiences change beginning with the onset of a family member's mental illness through their involvement in a family group or peer-education program as participants then facilitators. The findings of this qualitative analysis may elucidate the inherent value of being a facilitator and contribute to the program's dissemination, thereby increasing opportunities for education and emotional support for more families.

METHOD

Interviews of Facilitators

We used purposive sampling by choosing sites with high adherence to the program's aims and procedures to identify facilitators' experiences that were representative of the program. We used the program's fidelity scores from 2010 because a high fidelity score reflects high adherence to the program's manual (Ninomiya, 2012). Five of the 18 program sites with the highest scores were chosen, and 3-6 facilitators from each site were interviewed in groups at each site. Four sites were in areas around Tokyo and one was in West Japan. A total of 24 facilitators from the selected sites were interviewed. To obtain rich descriptive data, three facilitators, who were members of the project's team were interviewed because of

their long experience with the program. Two of the facilitators conducted the program at the same site, and the other was based at a different site. We conducted the interviews separately at each site. A total of 27 facilitators were interviewed and the participation rate in the interviews was 100%. One staff member of a prefecture's family association attended the interview as an assistant to clarify the information obtained.

Data Collection

The group interviews were conducted at each site to confirm information about the program's implementation, which was needed to grasp the experiences of the facilitators. We approached a representative at each of the 5 program sites with high fidelity scores, explained the interview's purpose, and requested all facilitators' participation at each site. All of the sites agreed to the interviews after obtaining the interviewees' agreement to participate. The group interviews lasted 2.0–2.5 hours with 3–6 facilitators at each site. A total of 7 interviews were conducted with 27 facilitators from 7 program sites, including 3 additional interviewees, between August 2012 and January 2013. The first and second authors, who were qualified nurses on the project's team and had experience doing qualitative research, conducted the interviews in tandem. One nurse facilitated the group interview while the other took notes and served as a secondary facilitator. We tried to promote the recall of the interviewees' experiences by facilitating group dynamics. We encouraged the interviewees to talk freely and used facilitative communication skills because we were concerned that they might not talk about the program's flaws with project members present.

The interviews began with the following questions that were answered by each individual: "What were your experiences from the time of your family member's onset of illness until you reached out to the family group, and after you attended the group?" and "How and why did you become a facilitator?" Next, all of the interviewees were asked the following question to obtain information about the program's implementation: "How was the

program conducted?" We also asked each interviewee, "What changes did you notice in yourself or your ill family member and your family's group activities during and after your time as a facilitator?" If an interviewee did not speak, we directed the question specifically to that individual.

Data Analysis

We conducted a qualitative descriptive study using naturalistic inquiry methods, which are appropriate for pure descriptions of phenomena (Sandelowski, 2000). We used content analysis and grounded-theory techniques (Sandelowski, 2000), including continuous comparative analysis (Strauss & Corbin, 2004) to describe hitherto, unexamined caregiving experiences and processes related to this program

The interview data were recorded and transcribed. First, we came to understand the facilitators' experiences as a whole at each site by reading the transcripts repeatedly. Next, we analyzed data from each facilitator, comparing them with each other, using the continuous comparative method (Strauss & Corbin, 2004). The transcripts were processed line-by-line using open coding and labeling of content related to the following research question: "What did facilitators experience before, during, and after being facilitators?" The coding was compared for similarities and differences, and similar content was categorized. The properties and dimensions of the categories were developed. Connections were made between categories using their properties and dimensions to perform axial coding. The following properties were found to be especially important: the degree, quality, period, causes, and changes related to each of the caregivers' experiences. As axial coding proceeded, we found that caregivers' changes in caring experiences were related to the value that they placed on their experiences. The stages of processes often are described by examining the sequences or shifts in actions/interactions (Strauss & Corbin, 2004). When we identified the actions/interactions that served as a bridge to subsequent actions/interactions along with the

conditions affecting them, and their shifts to the next actions/interactions, we considered these shifts as a sequence of stages. Diagrams and story lines were developed and revised through discussions during the selective coding process. We recoded and recategorized the data until common themes describing the facilitators' progression through the stages the caregiving experiences were identified.

To ensure the study's rigor (Lincoln & Guba, 1985), the authors who were experienced in qualitative methods analyzed the data independently and confirmed each interpretation of the data and resolved disagreements through consensus. The study's rigor was increased by requesting all of the interviewed facilitators by mail to endorse the results from the perspective of a typical facilitator. Only two of the 27 facilitators wrote that part of the results did not fit with their own experiences.

Ethical Considerations

This study was approved by the Ethics Committee of Saitama Prefectural University (no. 23023) in Japan. The interviewed facilitators were informed verbally and in writing of the study's purpose, their right to refuse to participate, and the voluntary nature of their participation. The interviewees consented to participate in writing.

RESULTS

Demographic Characteristics of Facilitators

The demographic characteristics of the interviewed facilitators' are shown in Table 1. Of the 27 interviewees, 17 were female and 10 were male. Over half were aged 70 years or older, and most were the mothers and fathers of patients. All of them were board members of the family groups and had experience as facilitators, averaging 2.5 courses (range: 1–6). Fifteen had qualifications as program advisors.

[Insert Table 1 about here]

Summary of Families' Caregiving Experiences

The five stages of the families' caregiving process began with a family member's onset of a mental illness, accompanied by caregivers' negative experiences. The family's way of life that was dominated by their experiences as caregivers, unfolded by sharing their experiences as participants in the family groups and then as facilitators in the Omotenashi-FELP. The value that they placed on their experiences shifted from negative to positive, which was apparent in their ability to support participants, learn from each other, and then help other families. This process is shown in Figure 1.

[Insert Figure 1 about here]

Story line

The interviewees' negative experiences included difficulties and regrets caused by their loved one's onset of mental illness, which were kept private within the family. Families somehow attended meetings to share their experiences and found comfort in other families' empathy. They became facilitators in the Omotenashi-FELP and used their experiences to support participants. As they shared experiences many times, they understood their previous ways of living and affirmed them. Facilitators recognized commonalities between the current participants and themselves as they were previously, and saw positive changes in participants over time. These changes made facilitators aware of the value of their experiences and encouraged them to help more families in need. Finally, facilitators found unique social roles through their experiences, and led their lives with a new sense of value. The latter stages were reached by serving as facilitators in the program.

Experiences of Facilitators at Each Stage of the Caregiving Process

The interviewees are described as families in the first and second stages and facilitators in the third through fifth stages; all interviewees who reached the third stage were facilitators.

First stage: Withdrawing and suppressing negative experiences with difficulty

and regret. The majority of family members found they had no opportunity to express the difficult experiences they faced after their loved one's onset of mental illness. The inability to express their negative experiences led to their isolation. For many of the families, their experiences began at this stage, as they lived and functioned predominantly as caregivers. Two family members said their responsibilities as caregivers "disturbed my daily life" (No. 26) or "made me not prepare meals" (No. 27).

Difficult experiences as a family. Families attempted to manage the situation in various ways after the illness's onset. However, the patient's condition generally did not improve, and it was not uncommon for the family members with mental illness to attempt suicide. Families had to monitor their loved ones constantly and endure extreme anxiety and stress. A family related the following incident: "My daughter ran away when I did not keep my eye on her. She had an electric cord around her neck. It was so hard" (No. 26).

Regretted behavior and regrets of insufficient knowledge. Families looked back on their difficult experiences, as illustrated by the following statements: "My way of handling the situation was bad" (No. 12), "I could not do anything" (No. 4), and "I could not rescue him" (No. 9). Difficulties became negative experiences characterized by regrets of having insufficient knowledge and coping strategies. Families often blamed themselves for failures despite their efforts to manage difficult situations.

Withdrawing and suppressing discussions of one's experiences with others. Families could not reveal their negative experiences to anyone; therefore, they kept them to themselves, e.g., "agonized by myself" (No. 16), and became isolated.

After a period spent withdrawing and suppressing their negative experiences, families attended meetings to share their experiences with other families. As a family said: "It took 2 years to reach the family group" (No. 1). Their communication with other families marked the beginning of stage 2.

Second stage: Finding comfort through being listened to about negative experiences. In this stage, families met, many for the first time, other families who were caring for a family member with a mental illness. Families talked freely about the negative experiences they were unable to talk about previously, and felt a sense of relief when other families listened to their stories and empathized with them.

Recognition of empathy from peers. Families recognized qualitative differences between the empathy of their peers and that of professionals. A family described peer-empathy as “feeling with my own body” (No. 22). Another family said, “Professors and doctors give good lectures but they have not actually struggled. Our families’ experiences are real experiences, so families can feel empathically” (No. 11).

Feeling comforted by being listened to when sharing experiences with other families. Some families found comfort in sharing their experiences and being listened to after reaching out to the family groups. A family said: “I could not tell anyone about my son’s mental illness. I felt sad and close to tears every day. When I attended the family group, they listened to my entire story and I was relieved” (No. 10).

Families’ experiences of being listened to and receiving empathy from peer families impacted their actions in the next stage; as one family said:

Families who have not been accepted by other families feel guilty about having made their family member sick. They felt blamed that they could not handle situations well when other families talked about their successful ways of coping. Although we threw a round ball to them, the ball became a triangle or a square when they caught it (No. 27).

After sharing experiences with other families as participants, most families were asked to be facilitators by the other facilitators. Some were highly motivated but some were not at the time.

Third stage: Supporting participants' sharing as facilitators. In this stage, families functioned in their new role as facilitators in the Omotenashi-FELP. When facilitators led the discussions, they used their prior experiences to elicit participants' experiences. A facilitator described this method as "priming water" (No. 23). The experiences of each family in the second stage were internalized by the families and became the behavioral standard used by facilitators to support the other families. A facilitator noted the following experience: "When I attended the program as a participant, facilitators listened to my story very well, accepted me, and told their stories honestly. It made me feel at ease. I want to support participants as a facilitator in the same way" (No. 2). By implementing the program as facilitators, they used their experiences, which were previously negative ones, to support the participants. However, they only used their experiences as a vehicle to facilitate the Omotenashi-FELP during this stage. They were not aware of the true value of their experiences yet. As they shared their experiences repeatedly, in the next stage, their awareness of the positive value of these experiences became apparent to them.

Fourth stage: Understanding and affirming oneself through repeated sharing of experiences. Facilitators who repeatedly shared their experiences understood their previous ways of living and were able to affirm them.

Understanding oneself. Sharing their experiences helped facilitators understand themselves. A family member said, "I could see myself from the perspective of a third person when I heard others' experiences" (No. 6). Facilitators found it helpful to organize their experiences in a timeline of issues and events from the onset of the family member's mental illness. One facilitator said: "I had read dozens of books but the knowledge in my head did not take root in me. When we shared the sequence of our own experiences from the onset with other families using the textbook, I could organize my experiences well and make sure that what I had done was alright. I think my understanding was due to repeating my role as

facilitator in the program” (No. 24).

Affirming oneself for overcoming negative experiences. Facilitators who overcame negative experiences affirmed them, although the negative experiences still existed. A facilitator said, “I wondered why such a tragedy happened to me. Through the program, we recognized our attitudes and behaviors, faced the tragedy, and handled related issues. We should be proud of ourselves” (No. 22).

Facilitators who understood and affirmed themselves developed a broader view of themselves and the participants. This change marked the beginning of the final stage. Facilitators who did not acquire a more open understanding of themselves remained in the fourth stage and some functioned in fourth and fifth stages simultaneously.

Fifth stage: Finding value and social roles in one's experiences. In this stage, the positive value facilitators placed on their experiences was useful to participants and other families in need. The facilitators found new social roles for themselves and wished to help more families in need.

Finding value in experiences that are useful to others. Facilitators enjoyed observing participants' expressions change from non-expressive to cheerful. They saw participants as they saw themselves in retrospect, so they felt deep empathy and strongly identified with participants' emotions and experiences. A male facilitator broke into tears when talking about a participant with whom he had much in common:

He was the same age as me. He was busy at work so he could not help his son with mental illness, or his wife to cope with it. His situation was the same as mine. The first time he attended the program was the first time that he was involved with the illness. At the final class of the course, he said that he was now the person who understood his son best. That was the most impressive thing for me and most pleasurable thing as a facilitator (No. 22).

These feelings of satisfaction made facilitators aware of the value of their experiences in helping families similar to their own. One facilitator said, "If families want to know about the illness, they can go to a professionals' lecture. However, they come to us. I think that our real experiential knowledge is helpful to them" (No. 2).

Desire to help families in situations similar to their own previous situations.

Facilitators' awareness of how their experiences could help other families created a desire to help them, which influenced their actions inside and outside the program. A facilitator described this experience as follows:

My son acted violently and was admitted to psychiatric hospitals. I did not know anything at the time. Therefore, I wanted to rescue other families who were struggling and isolated. I decided that I would support them in the family group and the program (No. 4).

Finding one's social roles and leading one's own life. Facilitators aware of the value of their experiences found social roles that were unique to experienced families and led their lives in their own way, including as caregivers. A facilitator described the changes to her way of life as follows:

I think that the experiences related to my son's illness are a part of my present self. I have a broader and different perspective from my past self. When I overcame it, another way to live opened. It is as if I see wonderful scenery when I climb a steep mountain road and reach the summit. I am glad that my husband appreciates me because I am doing what I should do (No. 27).

Experiences in the program and the family groups

Most families experienced the third, fourth, and fifth stages in connection with serving as program facilitators. However, there was a combination of experiences among the family group participants, program participants, and program facilitators in the second and

part of the fourth stage. The differences in families' experiences were sometimes related to the family group's failure to provide mutual help to its members. Some families found empathy for the first time only when they became participants or facilitators in the Omotenashi-FELP. A family said the following: "The topics in the family groups were only about running the rehabilitation facility. I experienced real talking with other families about our stories the first time in the program as a facilitator. I felt it was new" (No. 22).

DISCUSSION

Facilitators' Caregiving Process and the Program

We identified five stages in the families' caregiving process that changed through their involvement in a family group or peer-education program as participants then facilitators. The third, fourth, and fifth stages of the process were associated with service as facilitators. Not all of the families in this study experienced all of these stages, nor did the stages always occur in sequential order. Their progressions through the stages mainly were affected by their experiences in the family groups. Families could experience more than one stage simultaneously and there was no backward movement through the stages. Finally, the facilitators found their own social roles in their experiences and pursued their lives with a new sense of worth.

Lucksted et al.'s (2008) study of the FFEP reported that participants gained information, understood their situation, and incorporated the perspectives of others. These findings are similar to our fourth stage, "*Understanding and affirming oneself through repeated sharing of experiences.*" However, their findings do not include the families' experiences that we observed in the fifth stage of our study, "*Finding value and social roles in one's experiences.*" Therefore, it may be that the fifth stage is experienced by facilitators, but not by participants in family peer-education programs.

The process observed in this study may be similar to the one experienced by members

of self-help groups. Borkman (1999) reported that some individuals who reached the final stage, referred to as “Thrivor” in that study, were willing to lead self-help groups or help others in ways that were more substantial. This transformation is similar to the process described in the present study, possibly because the Omotenashi-FELP is based on family self-help groups. Theoretically, both processes may be the same; however, the actual experiences in Japanese family groups are different from those described by Borkman (1999).

In this study, families attended meetings to share their experiences with other families and moved to the second stage, “*Finding comfort through being listened to about negative experiences.*” Participants of the FFEP progressed until the fourth stage of this study, “*Understanding and affirming oneself through repeated sharing of experiences.*” However, the facilitators moved to the fifth stage, “*Finding value and social roles in one’s experiences.*” This finding suggests that there are different meanings in the experiences of facilitators and participants in the peer-education programs and family groups.

The most important difference between the facilitators and participants was whether their objectives were intended to benefit others or themselves. Participants were passive and acted for themselves as the second stage suggests, “*Finding comfort through being listened to about negative experiences.*” However, facilitators acted for others, as described in the fifth-stage category, “*Desire to help families in situations similar to their own previous situations.*” The facilitators’ and participants’ similar experiences as families strengthened their empathy for one another (Davis, 1994). The illness duration of the family members with SMI was shorter for participants than for facilitators. Therefore, facilitators saw their previous selves in participants’ lives and expressed deep empathy, such as “feeling with my own body” (No. 22). This may have led them to act with “empathy-induced altruistic motivation,” as described by Batson (2011). They were aware of the value of their experiences that they previously viewed as solely negative, which we categorized as “*Finding value in experiences*

that are useful to others.” They felt confident that their experiential knowledge was “helpful to them” (No. 2). These changes may have occurred when facilitators supported participants. Based on supporting theories and this study’s findings, we conclude that serving as facilitators promoted families’ caregiving processes.

The Program in the Context of Japanese Culture

We have two possible explanations for why being a facilitator promoted families’ caregiving processes in the Japanese context. The first explanation is that there are limited opportunities for family to share their experiences. The families in this study described peer-empathy as “feeling with my own body” (No. 22), from which the category of “*Recognition of empathy from peers*” was derived. Peer empathy has a special value for Japanese families. However, when Japanese family groups operated small rehabilitation facilities, some groups lost sight of their purpose to provide mutual help. The Omotenashi-FELP was the first to give mutual help, even to participants who belonged to family groups. Through participation and facilitation in the Omotenashi-FELP, most of the families progressed through the stages of the caregiving processes.

The second possible reason is that Japanese facilitators may be at an earlier stage of the caregiving processes than the facilitators in the FFEP when they become facilitators. The Omotenashi-FELP requires 3-6 facilitators per program site. Therefore, even families who are not highly skilled as facilitators, are asked to assume this role. Facilitators in the FFEP, however, usually are selected families with a high level of facilitation skills. The difference in facilitation skills is evidenced by the fact that the FFEP serves participants caring for untreated as well as treated patients (Corrigan, Mueser, Bond, Drake, & Solomon, 2008). However, the Omotenashi-FELP serves only participants caring for treated patients. Thus, the difference might reflect their progression among the stages in the caregiving processes. Japanese facilitators may be at an earlier stage of the caregiving processes when they become

facilitators; therefore, the Omotenashi-FELP facilitators may show greater success in their progress through the stages than the FFEP facilitators.

Implications for Future Programs and Study Limitations

The results have implications for program implementation. First, repeat facilitators are more effective at self-development and should be encouraged to facilitate several sessions rather than one or two courses. Second, it is important to listen to participants' stories empathetically, as their experiences as participants may become the future standard for facilitators. Therefore, the current behaviors of the facilitators are important to the continued propagation of the program.

This study has several limitations. First, group interviews were used to collect the data. Therefore, interviewee's comments might have been affected by the presence and statements of other interviewees. Another limitation is that we cannot say that the limited number of interviewees are representative of all facilitators. These facilitators were motivated; less motivated facilitators might not have had the same experiences. The homogeneity of the facilitators' age also may lead to limited generalizability of the findings. Almost half of them were in their 70s and none of them were in their 40s or below.

Conclusions

The caregiving process of families who became facilitators in the Omotenashi-FELP began with negative experiences, including difficulties and regrets; however, the value of these experiences changed through a series of five stages, in which they repeatedly shared these experiences with peer-family members. Families acting as facilitators in the program experienced the third, fourth, and fifth stages of the five-stage process; thus, serving as facilitators in the program may promote family caregiving processes.

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Table 1.

Characteristics of the Interviewed Facilitators and the Patients (N = 27)

Characteristics		n/Mean \pm SD (range)
Sex	Female	17
	Male	10
Age	50–59 years	8
	60–69 years	5
	70–79 years	13
	80 years	1
Relationship to the patient	Mother	16
	Father	7
	Sibling	2
	Step-sibling	2
Membership in the family group (years)		11.3 \pm 6.9 (2–26)
Role in the family group	Board member	27
	Regular member	0
Number of facilitators' experiences (courses)		2.5 \pm 1.3 (1–6)
Advisor qualification for the program		
Have		15
Have not		12
Patients' sex	Male	19
	Female	8
Patients' ages* (years)		40.0 \pm 12.8 (18–70)
Patients' diagnoses		
Schizophrenia		22
Developmental disorder		4
Depression		1
Patients' levels of functioning		
In psychiatric outpatient rehabilitation program		13
Working or studying without professional support		3
Not leaving the home		7
Hospitalized		2
Deceased		2

Note: *: excluding 2 deceased patients

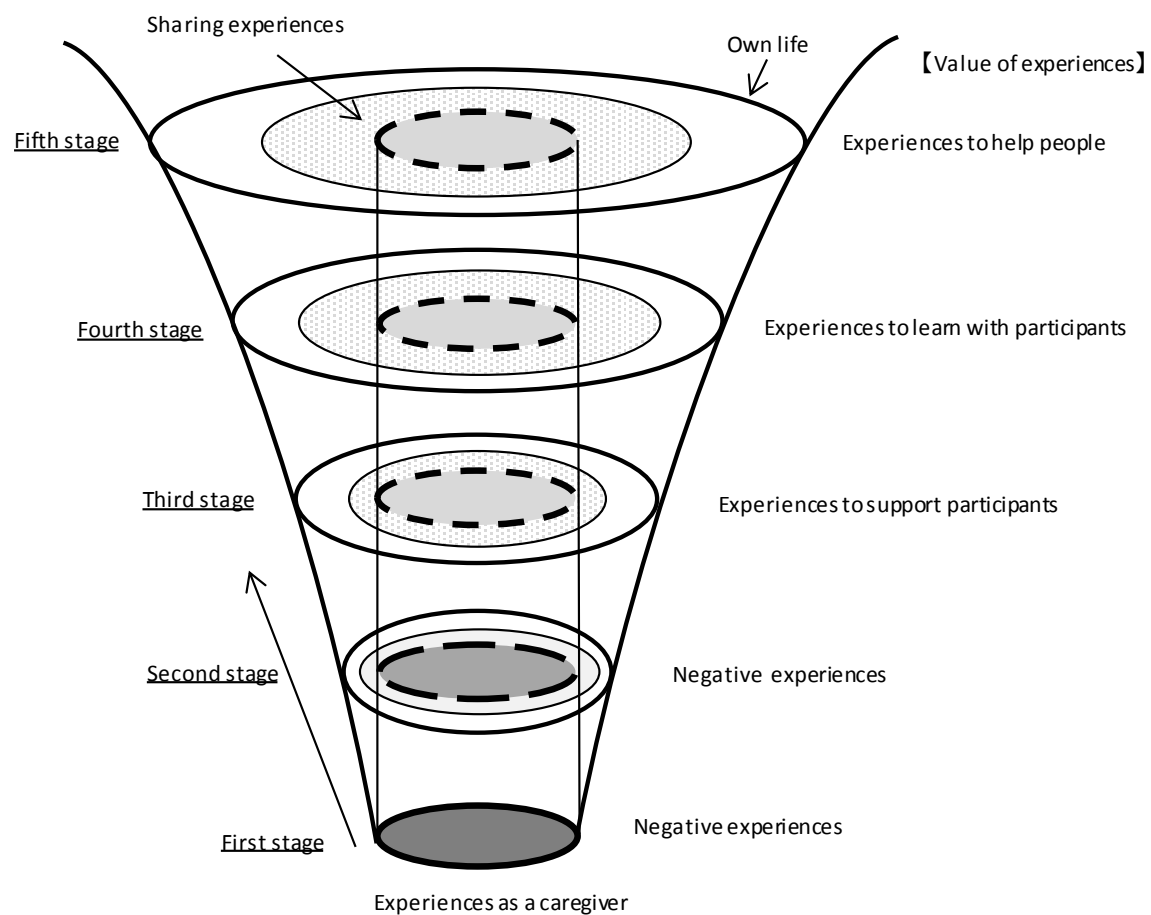


Figure 1. Changes in families' caregiving experiences through involvement as participants then facilitators in a family peer-education program